A Formula for Survival

A public health story from...

Dent County Health Center

ammy Winstead,* 27, brought her ailing baby son to the Dent County Health Center, determined to find out what was wrong. Lethargic for months, the infant experienced frequent bouts of vomiting and diarrhea. Tammy wondered if her son, almost one, could be suffering

from the same genetic disorder that afflicted her other two children.

Galactosemia, as the genetic disorder is called, is the inability to digest milk sugar; it occurs in one of every 40,000 Missouri births. Infants with the disorder may appear normal, but within a few days or weeks of breast milk or formula feedings, jaundice and lethargy may set in.

The condition can lead to mental retardation and death if left untreated.

If Tammy's baby had the disease, it meant two things. The milk-based formula the Dent County Health Center was providing to mother and baby had to stop--ASAP--and, there had to be a record of the infant's condition.

"You see," explains Roma Jones, the center's nutritionist and Women, Infants and Children (WIC) coordinator, "Missouri law mandates that every newborn be screened for a variety of disorders, and galactosemia is one of those disorders. I knew there had to be a record."

"...I knew there had to be a record of the baby's disorder..."

So Jones, a 16-year health department veteran, started digging and discovered a slipup. Tammy's son did have the disease, which had been recorded properly at birth, but Tammy's doctor had failed to tell the young mother.

"When the doctor discovered the mistake, he immediately wrote an order to put the baby on a special soy formula, rather than continue with a milk-based one," says Jones. Tammy's baby will also have to avoid legumes, organ and processed meats, and any other foods that contain milk for the rest of his life.

Jones says the center's WIC program, which provides supplemental foods such as formula, milk, cereals, fruit juices, beans and peanut butter to 500 financially needy women and children every month, had never dealt with a baby who had galactosemia before. "If there's a next time, we'll be prepared. But thank goodness we caught it this time."

*(The case described is real, but the name has been changed).